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CHRONIC ILLNESS AMONG THE SCHOOL AGE CHILDREN

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ABSTRACT

School age is that phase of life when children become quite conscious and expressive in terms of their problems. They are quite accurate and quick to report about any of their pain or illness to the parents and teachers (Azize, Humphrey, Cattani, 2011). In the words of Maternal and Child Health Bureau, "Children with Special Health Care Needs are those who have or are at increased risk for chronic physical, developmental, behavioral, and emotional conditions and who also require health and related services of a type or amount beyond that required by children generally" (McPherson, Arango, Fox, McManus, Newachek, Perrin, Shonkoff, & Strickland, 1998). There has been found variation in chronic stability and predictability (Brown, Daly,& Rickel,2007). Thus, child with chronic illness of lesser predictability, such as asthma, epilepsy, and diabetes leads to lesser degree of stability in comparison to the arthritis that has higher level of stability in the child's and his family's life. Family and parental influences on the school functioning of a chronic child has been widely explored.

KEYWORDS: Child Health Bureau, Chronic Child, Developmental, Behavioral, and Emotional Conditions

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INTRODUCTION

Children are in constant interaction with their parents, peer-groups and relatives that gives them a sense of developing social and behavioural skills. Studies have also revealed that children of such parents who themselves involved in social networking do tend to show the same behavior (Romano, Hubbard, McAnliffe, & Morrow, 2009). Specifically talking about children with chronic disease, they tend to show poor social skills, such as, having fewer friends, being in isolation, less interaction with parents, etc. in comparison to those without the same.

Such children also fail to maintain their studies and academic achievements (Ho, Bennett, Cox & Poole, 2009), especially, due to the occurrence of certain neurological diseases (Schatz, Finke, Kellet, & Kramer, 2002), such as, sickle cell disease. The chronic condition of children greatly affects their performance in school such as shortage of attendance (Stang & Osterhaus, 1993). Numerous factors are associated with absenteeism in children with chronic illness. Taking medical factors that consists of course of the illness (constant,progressive, or relapsing), onset(acute or chronic), degree of incapacitation and physical restrictions(Fowler et al, 1985) and the type of treatment(Cairns, Klopovich, Hearne, & Lansky, 1982) and demographic factors such as parental education, etc. In certain other studies conducted on school children, where the causes of absenteeism were reported as asthma, diabetes, etc. that led to affect the school performance of children in the form of reading-writing problem, grade repetition, learning disabilities, and behavioural problems. Children with asthma from low

socioeconomic families had been found to have twice the risk for grade repetition than their healthy counterparts (Gortmaker et. al., 1990).

Theoretically, emphasis has been given to two perspectives of family, i.e., the family composition perspective and the family process perspective. Under family composition perspective weightage is given more to the structure or type of family. Here, distinctions are made between single parent, non-biological parents, etc. while the theorists who argue for the family process perspective, based the theory on the quality time spend between parent-child, their positive relationship, sharing of problems, prevalence of calm atmosphere in home, etc. This, according to them, associate with or give yield to feeling of security and faith to children towards their family members that ultimately leads to psychological well-being of children. In families, there are various factors of different levels that contribute to the psychological well-being of the child. For instance, socio-economic status of a home having only one salaried member will be less stabled or satisfactory than that having both the parents working, etc. There has been conducted various studies that make this information strong that family environment does affects the cognitive development of a child. It has been observed that a child performs above average in school if he receives proper encouragement, healthy environment, protection, love, and check on his behavior regularly than the one who lacks all these essential elements in his family environment.

Goldsmith (2000) too, favoured the idea. The family pediatric report has revealed that when father in a family carries his responsibility with full concern and devotion the child is less likely to show negative side of his personality, the child exhibits proper social and emotional behavior and applies better coping strategies and adaptation skills. Their relationships are long lasting, having better problem solving capacity and higher level of productivity in work.

In relation to the above mentioned situation, when a child is a sufferer to any chronic mental or physical illness this becomes a source of great agony to that family. One such study conducted in India where, the main objective was to explore the main difficulties faced by those families and parents whose children are suffering from cerebral palsy. It was found that parents of such children were quite disturbed thinking of their children's future. Specially, mothers issues of major concern were happy moments, need for support services, disturbed social relationships, health problems, financial problems, and unavailability of adequate number of trained physiotherapists. These were certain major elements that were quite common among all the mothers. This gave an idea that parents of such children were experiencing wide range of psychosocial problems (Nimbalkar, et al., 2014).

Family functioning can be influenced variedly based on the differential levels of child's chronic pediatric conditions. For a wide range of time, the emphasis is based more on biopsychosocial models and ecological models in order to understand the chronic pain and its associated disabilities. The biopsychosocial model originates from social learning theory and applied to adults with chronic pain (Fordyce et al., 1973). Various studies have been administered in support of this. Family functioning of children suffering from various diseases or chronic illness, such as, cystic fibrosis, obesity, epilepsy, inflammatory bowel disease, have been assessed deeply in these studies. This helped in elucidating greatly about the level of effect of these pediatric conditions on the family environment, structure and processing in varied manner. Thus, there can be marked importantly that based on different chronic conditions of a child and its characteristics functioning of any particular family can be affected differently.

The purpose of the present study is to review the studies that are working on the area of family function with different range of pediatric conditions faced by their children right from childhood to the age of adolescence. There emerge two broad perspectives to this. Firstly, to measure the impact of childhood illness on the family and secondly, the impact of

family function on child's illness or disease symptoms. In the first situation, the family needs to get adaptive to the child's chronic biological conditions. This adaptive nature will only be yielded when psychological intervention programmes will be applied to the family. The second perspective focuses on the family's contribution to maintain the chronic biological condition in the child. According to Minuchin & colleagues (1975), a child's chronic illness e.g., diabetes, psychosomatic asthma, etc, is a response to conflict in families such as over protectiveness, rigidity, etc. This overprotection over concerned attitude may serve to increase pain behavior in children and can ultimately lead to increased disability (Peterson & Palermo, 2004). Thus, to cope up with this adverse situation a wide range of such disorders have been treated as family system problems (Routh & Earnst, 1984).

Apart from physical response to chronic ailments child's emotional ones may also impact school functioning. A longer duration absence leaves the child with little contact of his peer group. This can create a social discomfort not only for the child but also for the adolescents with chronic illness. The child is surrounded with lot many mental pressures. He takes stress related to his illness, concerns about his friends' reaction towards his own chronic conditions, his lack of confidence in physical and academic performances, these all somehow become the cause of his willingness to attend the school and perform well. This concern may vary with the change of phase of child's life. For example, peers of the chronic child in junior classes may think of his disease as contagious, while the peers of an adolescent may avoid him due to the fear of interacting with the person with some differences in health related issues, etc (Davis, 1989).

From family perspective, several models have been designed that emphasized on adapting to the chronic illness, considering it to be the stressor to the life of child and his parents, adaptive strategies should be performed in a regularized and continuous manner while during which coping strategies should also be performed to cope up with the situation effectively.(Thompson & Gustafson,1996).

Family Influence on the Academic Performance of an Adolescent

The extent of chronic pain becomes higher and stronger during the adolescent period (Roth-Isigkeit, et al., 2005). This may occur in association with pubertal development and other physical, cognitive, emotional and social changes in adolescents. For example, abdominal, musculoskeletal pain, headache, migraine, etc. The key features to the adolescent phase are autonomy or separateness from parents and other family members on emotional grounds. That seems to be critical a matter of great concern in performing a balance (Evans, Meldrum, Tsao, Frayant, & Zeltzer, 2010). Studies reported that higher level of family or parent interference on the personal space and freedom of adolescents leads to increased youth functional impairment and higher level of depressive moods (Lewandowski & Palermo, 2009). In a preliminary study with adolescents suffering from sickle cell disease, frequent involvement of parents in pain and disease management led to higher level of youth disability (Oliver et al., 2011).

Biological, psychological and social developments are highly interrelated and one may affect development in other domains. Delayed growth and puberty is common to most chronic illnesses, although more frequent in those where malnutrition and chronic inflammation are most common. For example, bowel disorders, cystic fibrosis, etc.). Delayed puberty may result in low self esteem and difficulty in separating from parents due to apparent immaturity. They may perhaps be treated as less mature than their actual age by elders and peers. The well-being and healthiness of a chronically ill adolescent is determined largely by the severity of the disease and amount of medication required. Apart from this, psychological and social implications may also play major roles in such conditions.

Vast number of studies and research works are undertaken that has emphasized greatly on adolescents' coping strategies with regards to their relationship with pain behavior (Reid, Gilbert, & McGrath, 1998). For example, passive coping strategies that generally involve orientation at distant from stress provoking sources and include such behaviors like, self-isolation, catastrophizing, and disengagement. These are associated with higher levels of pain, somatic symptoms, depressive symptoms and functional disability (Kaminsky, Robertson, & Dewey, 2006). Whereas, in accommodative coping strategies efforts are made to adapt to the stressor, such as acceptance, minimizing pain, self encouragement, and distraction. These strategies have been associated with both lowered initial pain and reduction in pain with passing of time (Walker et al., 1997), fewer somatic complaints, and also lower levels of anxiety and depressive symptoms(Thomsen et al., 2002). However, there is a mix of results on active coping strategies that emphasize on to change or influence stressful situation, such as, problem solving and social support seeking. Some research report about increase in the somatic symptoms, pain and dysfunctioning (Compas, Connor-Smith, Saltzman, Thomsen, & Wordsworth, 2001), while other studies indicate that these strategies lead to decrease in chronic pain symptoms (Reid et al., 1998)

Family Influence on Pediatric Chronic Conditions of Child and Adolescents

Scientists have made various modifications and changes in the assessments of child assessment methods. Family functioning is more likely to be investigated than any other variables to see its impact over the child suffering with chronic pediatric conditions (Wallander & Thompson, 1995). Because previous studies have reported about the essential features of family functioning that helps and provides support to the child in coping up with the chronic disease. Bandura's Social learning theories (1977) has been used often to emphasized on the relationship between child's chronic conditions and family functioning(Chambers, Craig and Bennett, 2002). Simons, Claar, & Logan (2008) examined relations among parental responses, adolescent pain and pain behavior with chronic pain. Adolescents were administered using various assessment measures to assess their pain, pain coping responses, functional disability and somatic symptoms. It was reported that parental responsiveness towards their child chronic pain may be an important target to treat adolescent pain.

There are five important characteristics of family functioning commonly assessed in family system theories are organization, cohesion, communication, affective environment and problem solving (Alderfer et al., 2008). It is a natural phenomenon for a parent to get involved into a distressing situation seeing his own child to be a victim of chronic pediatric condition. Family functioning encompasses several constructs (Rolland, 1993). Various researches have too indicated that parents of such children are under great anxiety; depression and parent role stress (Eccleston et al., 2004). However, this is the issue of further investigation whether these symptoms lower the pain conditions or develop in response to parents concern towards their child's chronic pain.

This has been further reported in those studies that amongst the parents, mothers are more likely to be fallen under prevalence of anxiety disorders and depression (Campo et al., 2007). Further, it has been indicated that maternal distress and childhood chronic pain are likely bidirectional in nature. A child's perception of pain is related to his or her physiological, biological, current emotional state, pain behavior and functional disability. His perception of and response to pain and the developmental trajectories are influenced by both parental characteristics, such as, parents behavior, emotional functioning and medical history through the parent-child interactions, family factors, i.e., family functioning, family size, family environment and life-cycle stage. Thus, these all variables contribute in creating a bidirectional relationship. In support of this, a study was conducted that reported using path analysis about the relationship between caregiver variables and pediatric chronic pain and disease, where researchers found that mother's depression was a direct predictor of child

depression in children with chronic pain (Williamson, Walters & Shaffer, 2002). Similarly, Rhee et al.(2003) expounded that parent's cognitive and behavioural function in reaction to children's chronic pain also play major role. Chronic pediatric conditions of a child might prove to be distressing not only for his parents but other family members too. That may further lead to the disruption in any planned events or happenings that can be the source of overall imbalance in family functioning, such as; communication gap leads to poorer pain management strategies for the child. Developmental phase of child too may have its influence over the life-cycle stage of a family. There is a transitional process that takes place in the roles and characteristics of each family member through different phases of life. For example, it is a very challenging task for a parent to take care of a small child so as to assist them in developing early socio-emotional skills, while parents of an adolescent may have to work on promoting autonomy to him with proper guidance and moral assistant. However, in certain previous studies it was reported that despite having differences in treatment regimens, disease course and prognosis, children have similar family function. This has been found consistent to not only among the children affected with the chronic diseases but also those who were medically fit.

Families of children suffering from obesity or sickle cell disease appeared to be at greatest risks based on clinical intervention reports. This was more prominent if there was less contact or poor communication between the pediatric child and his family. The major source of this occurrence was either hospitalization or medical crisis that resulted in loss of quality time needed to be spent with chronically ill child. Thirty-six percent of families demonstrated below average functioning with respect to division of responsibility for fulfilling the family roles. In a recent study by Simons, Claar & Logan (2008), the essentiality of the role of families has been emphasized over the treatment of an adolescent suffering with chronic disease. This outcome has been consistent to several studies in the past where the majority of results have come into the support of important role of family factors on adjustment (Drotar, 1997; Eccleston et al., 2004) and functional parts (Schanberg, Keefe, Lefebvre, Kredich, & Gil, 1998) in adolescents with chronic conditions. According to Rolland's typology of illness and various other prior studies, there are various pediatric chronic conditions that require complex daily and regular treatment along with ongoing monitoring to attain positive health outcomes. Further, roles of family members could also be exchanged during acute period of pain. For example, if a child is hospitalized, one caregiver should stay with him while the other one can manage with household works and take care of child's siblings. These strategies have found positive clinical outcomes. In this manner, families may implement certain strategies so as to make certain improvements in the chronic pediatric conditions of the child by arranging proper communications, time management, and conflict resolutions. This will be enhanced in a noticeable manner and frequently if roles are performed equally and in a negotiable manner.

Within clinical settings and observations, this will also help in identifying specific areas or factors due to which families may experience difficulty that will further guide clinical intervention and strategies. In developmental studies on family functioning, later child age is associated with poor communication, affective responsiveness and general functioning, while adolescents are accompanied by attempts to achieve increasing level of autonomy and challenge parental authority that leads to grater family conflict, less parent-child interaction, and poor communication. Significant differences on roles and affective involvement were also found for household incomes with poorer functioning for lower income households. As a result, lower SES too linked with greater marital conflict and parenting stress. However, there were also found certain discrepancies in certain studies where better communication and general functioning were linked to a higher number of children living in the home. This indicated that presence of more number of children at home necessitates frequent direct communication and support network coping and up with routine difficulties and making daily

decision making function. However, prospective studies should examine the role of important variables in proper family functioning. The pain complaints are often being made by the children of those parents who themselves too always under the flare of pain (Levy et al., 2004). One potential factor for the occurrence or feeling of pain in particular family is, parental modeling of pain behavior. Children also report the similar locations of pain as their parents (Evans & Keenan, 2007). There are various lab based tests that have laid great emphasis on the importance of modeling in children's response to pain. Another major factor for parents' impact on children's chronic pain is family relationships or patterns of interaction among parents and children with chronic pain. It was reported by that in order to provide protection to their children parents of chronically ill children are more anxious than those of children without pain (Ramchandani et al., 2006). They allisability and ow and encourage children to avoid any hectic schedule, limit family activities or not to send children anywhere except school (Lipani et al., 2006). In order to provide support and soothing effect to their children parents may become more caring, reassuring during their pain duration. While in adaptive responses, there are several parental behaviors that serve as a key to decreased chronic disease and disability. In one study, Sanders and colleagues (1996) found that particular parent behaviours were the significant predictors of improvement in children's recurrent abdominal pain. It was reported further that mother's use of adaptive care giving strategy

Intervention Programmes/Strategies to Control Chronic Pediatric Conditions

Certain studies have reported that the chronic pain in adolescents occur within a family context and works both as a medium and affect on the family system. Thus, it has been argued that effective intervention programmes and strategies not only to be implemented on the adolescents but also their families (Kazak et al., 2002). Thus, it is essential to provide a family based intervention schemes, as positive impact of treatment may not be shown up if parents and family members do not adapt to appropriate ways to encourage their children in making positive coping efforts. Parents should be taught to discard themselves from being overly protective, solicitous, and criticizing the adolescent's pain excessively will encourage functioning of adolescents towards their pain feeling in adaptive manner will lead to better outcomes for these adolescents (McCracken, 2005). In addition to adolescents, even their parents need extra support to cope themselves up with such adverse situation and the uncertainty associated with the accurate diagnosis and treatment of their children (Jordan, Eccleston, & Osborn, 2007).

Self-help agencies and organizations that bring families of individuals with specific diseases together can be helpful and supportive enough in organizing special events such as conferences, tours, etc. that promote exchange of ideas and pain experiences between adolescents facing similar situations. The nature of intervention and medium of delivery depends upon a variety of factors, such as, the quality of relationship within the adolescents, primary support group and the structure of differences and variations they are experiencing. This is interesting to mark that most of the interventions rely heavily on social learning theory and attachment theory. There are certain popular interventions and therapies that have proven impact on children and their families. Cognitive behavioural therapy: CBT is a problem solving therapy that focuses mainly on family unit rather than an individualistic approach. Here, parental involvement is considered to be a key factor in influencing outcomes, such as significant association between the parental and child anxiety (Gbham, Dads, & Spence, 1999) and depression(Bond et al., 2005). It has been revealed that this therapy helps in weakening the impact of depressive symptoms and feeling of hopelessness. Another type of therapy is Interpersonal psychotherapy (IPT) that focuses on an individual's present difficulties in functioning (Mufson et al., 2004). Its aim is to reduce depressive symptoms by improving the individual's interpersonal functioning. This has its origination from the attachment theory

(Bowlby, 1980). There is another significant therapy named as trauma focused cognitive behavioural therapy (TF-CBT) that helps in attaining the unique biopsychosocial needs of children lying between the age of 4-18 years and experiencing post traumatic stress disorders and other problems related to traumatic life experiences.

It involves separate sessions with the child and parents as well as joint sessions of both. Parents are involved in the treatment process to enhance support for child, reduce parental distress, processing the traumatic effect, managing distressed thoughts, feelings and behaviours; emotional regulation skills, stress management skills, enhancing safety, reeducation about healthy interpersonal relationship skills and teach family communication. In later stage of therapy, the other family members, such as, siblings may also be included into family sessions to enhance communications (Cohen, Deblinger & Steer, 2004).

Parenting programs can be implemented as an early intervention to prevent the onset of any problem such as chronic disease or to curb and improve its severity in high risk children and adolescents. Thus, the primary aim of any therapy or intervention programme should be to provide families with skills and efficiency in order to enable them to assist their children in increasing the adaptability and reducing the maladaptive behavior without destroying a secure, loving and consistent bond with them.

LIMITATIONS

Most of the studies have been conducted pertaining to parent interventions for preschool and early school aged children but lack in putting emphasize on the same for adolescents. One of the major factors behind this may be due to attainment of maturity adolescents are under less influence of their parents. In addition to this now they spare most the time with their peers, and available less at home that makes them reluctant to typical parental strategies (Kazdin, 2005).

Lack of longitudinal studies is also a significant problem in implementing parenting and child focused programs. Longitudinal studies are quite helpful in examining whether the effects of the intervention are sustained over a particular time-period or its positive effect emerge only after a significant period of time has elapsed. Through these studies it becomes quite easy too to find out the negative effect or portion of the intervention programs to make further modifications to that.

CONCLUSIONS

However, studies confirm that parenting is the most impactful and long-lasting medium not only during an adolescent period (Devore & Ginsburg, 2005) but afterwards too plays a role of great supporter to adolescents in transition to adulthood. Studies that have been conducted till now consist of certain specific limitations such as small sample size, high rates of attrition, inadequate randomizations, reliance on self-report inventories and focusing more on behavioural measures of mothers than those of fathers. Children observe and learn from their parents' response to pain along with its consequences. For example, Walker (1993) conducted a study on children with RAP and peptic diseases who had family members with frequent illness considered that they would also receive sympathy and console with less responsible tasks as similar to their ill relatives due to chronic illness.

Guiding parents and families regarding intervening their children's chronic disease is not only helpful to them but to their community too in reducing predictable fear and anxiety and to increase their adaptability and minimizing its effect. Many times, parents find it not appropriate to discuss their stress and concern with their children. That further brings on strenuous relationship within the families. Thus, in order to fix this problem various psychotherapies and counseling work

to soothe chronically ill children, siblings, parents and rest of the family members. These provide them a stage to express their pent-up feelings and latent fears so that to facilitate their working, emotions, understanding and relationship through various ups and downs of their lives. Following and implementing these counseling and therapies properly may provide a great relief to the entire family. Through counseling a feeling of trust, strong bondage and understanding develops in the family that ultimately help chronically ill children realizing and believing that their family understands him and is always present to protect them from any harm or undesirable situation. Additionally, it also helps family to gratify that they are not the only sufferers who are facing their children's chronic disease.

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